Identifying Key Local Information for Action Planning Transcript

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Right now, we're going begin to transition into the work for the day. And part of this work has to do with identifying key local information for action planning. Let me just get all of my materials together here. I'll just pretend I'm Steve, although I'm sure I don't sound like him. That's what I was thinking. I'm just not as tall and I feel kind of, less, because of that. I can't jog like Steve. That's for sure. Bad knees. I just wanted to say that there are two people in this meeting that I've known for a very long time. One is Harold Freeman. Harold and I first met in 1980, when I was just coming to work at Memorial Sloan-Kettering. And I came up to Harlem to talk about screening and cancer control issues in Harlem because I had actually done some work at Harlem when I was in high school. And I'd heard about Harold and I came to visit with him. Several years later, Harold began to wonder whether I worked at Sloan-Kettering or if I worked at Harlem Hospital because you used to see me almost every day in his office. And I wasn't sure if that was a good thing or bad thing, but we've gotten along and gotten to know each other. He's been a good friend. But the other person in this room that I've known for a really long time is Gil Friedell. And I was trying to remember, Gil, when we first met, but I think it was when you were the head of the Markey Cancer Center. And I believe you used to attend the AACI meetings, the American Association of Cancer Institutes. And we were on the cancer control task force, and I was coming to that meeting as a young investigator. And Gil, as long as I've known him, has been making the point about how issues that are problems in the community -- that the solutions lie in the community. So Gil, this slide is for you.

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I've come up with a new term. We're going to move from federalism to Friedellism. It's a whole new term. It's a new concept. I want you all to adopt it. I want to see it in all your papers, because Gil had said to me many times that if the problem lies in the community, the solution can be found in the community. I'm not sure that I got that quote quite right, but I hope it's close enough Gil. And this is a really important point. Because up to now, we've been looking at, sort of, national surveillance data, we've been trying to drill down to what we know on a regional basis, and it was really in the concept mapping exercise that we first began to learn, as Harold said, something about,

what the perspective is in the community. He made the point this morning that he's heard what we all think, but he's not yet heard necessarily what the community thinks. But let me just suggest that there are an awful lot of people here who are a lot closer to the community than I am at the National Cancer Institute. And so we are getting closer to that and I still think we've got a ways to go. But part of what we want to try and do today is to try and figure out what are some of the tools and to try and help you, provide you, with some models for tools that you might be able to use, particularly when you talk this afternoon about what you can do at the state level.

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So, I hope by now, I don't know, for sure, and Cindy, maybe you can nod yes or no, that the materials have been distributed to everybody MS. VINSON: (Inaudible.) DR. KERNER: Okay. Yes. Those of you who are patiently standing on line for your materials, thinking you were in an airport -- we will try and get that to you because you're going to need them for your -- . It's going to be more important, actually, at the afternoon session than it will be in the morning session. But I wanted to just briefly go over with you what we've tried to put together. So we did a survey of all the states that are here, in terms of their cancer control plans, but we also, with the help of Nancy Lee and some of her staff, particularly, Leslie Gibbon, who e-mailed this to me. Even people from the CDC, who are not at this meeting, are helping with this meeting, so that's the level of commitment we're getting from CDC and we're very grateful for it. You'll also see a map in your handouts that shows the current status, as assessed by CDC staff, of National Comprehensive Cancer control initiative state plans. And both Leslie -- Leslie tried to tell me this on the phone and Nancy reminded me last night, that what you see depends on who you talk to. So we called the states and we got one picture and you'll see some information about that. Each of your states -- you'll have a map. And it says, for example, I've got Alabama, here. The Alabama Cancer Plan. It will say who the contact person is and what the status of the plan is. And by and large it should line up with this map, but if there are any differences, it's probably because the person at CDC who they were talking with who's a little different than the person we were talking with. And Nancy and I were talking about when ACS did this, there was a slightly different version. And so, we're getting close to what we understand about the cancer plans. But each of you will know your state's well. But we wanted to provide that, just in case you didn't know about your state cancer plan. And the question we specifically asked was, is cervix included Is it part of the plan And so

you'll see information about that. In many states it's not part of the plan. So that's one thing. We've also developed these county fact sheets for you. Now what we did is -- we couldn't, we all know that the federal government has infinite resources, not true, but we tried to pick at least three model counties in each state. For those of you with states that only have one or two counties, you got 100 of your counties, but for those of you that had more than that, we picked three model counties, and we put some information together for you about who your federal and state representatives were. This is public information, of course. There's no implied promise and suggestion about anything to do with them. Information about women's community based organizations, information about the local breast and cervical cancer program leader, the CDC funded project. And we have a list of faith based organizations. And it's not to be exhaustive. It wasn't designed to say that this is everybody you would want to work with, but it was just some suggestive groups that potentially could be partners when you start talking about activities at the local level. You also have in your things, and I'm going to go into each of these in a bit more detail, local media contacts by state. I'll save that. That's actually on a disk in an Excel spreadsheet for you. And then, one of the questions that you may want to think about before this afternoon's session, when you start talking about local action planning is, what are some of other state and local resources that can help you to reduce cervical cancer mortality and eliminate geographic disparities in your state

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So here's the plan. Naturally, if Steve had been here, he'd be talking about Kentucky. So this is the model of what the Kentucky cancer plan sheet looks like. It shows that there is a comprehensive cancer control plan and that cervical cancer is addressed in the plan. It gives the website so that you can download it. It gives you the contact person for Comprehensive Cancer Control. And we've given you the CDC website so that you can go and check all the other information that CDC puts up on its website about Comprehensive Cancer Control, and CDC has been putting a lot of resources, particularly in collaboration with the ACS, to build, sort of, the leadership in Comprehensive Control.

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Lawmakers. I can't imagine what you might be doing with them. But you have a listing of the federal lawmakers, the state lawmakers -- for that county. And again, we only did this for three counties per state,

but obviously it would be relatively easy for you to find out who the -- I shouldn't say relatively easy, it would be something you could do to find out who are the critical lawmakers, particularly if the state level, are for that particular county, a high mortality county.

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County contacts for the CDC Breast and Cervical Cancer Program,

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women's health community based organizations. So you see we've given you the name of the organization, the address, the contact, as we could best put it together.

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Faith based organizations and examples of that. So again, not intended to be exhaustive, just to be examples of the kinds of groups that you may already be working with. Perhaps there's some that you didn't know about. If that's true, that's great. But there are other organizations that may also -- you may want to add to this list other types of organizations at the community based level that you might want to think about partnering with.

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Now these are the media contacts. This is a screen shot of the Excel spreadsheet that you've got on a disk. And the way you use it -- there's a little instruction sheet. But it can be used to produce a list of media contacts for your state with the disk provided in your region. You can search by state, so what we've done is -- I didn't quite state this correctly. Each region, by the way, has all the media contacts for all the states in that region. So if you've got a media source that's bordering on your state that has impact in your state. That may be just as important to you as a media source that's smack-dab in the middle of your state. So you can sort it by state, you can sort it by city -- I, of course, assumed that you could sort it by county. I was wrong. This sort, you can't do that. But obviously, you will know which cities are in which of your high risk counties so you can cluster your cities accordingly. You can sort by the type of media. And last night Vish, when he was talking about the important role media can play, mentioned the fact that it is newspapers, radio, television. There are all sorts of different media. And in the handout that you got from him, I hope -- . Did we do that, from Vish's presentation Good. In that you will see the different ways. The beat reporters. All the different

potential contact people -- so we hope that will be useful.

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And the bottom line of this message, which is consistent with what Gill has been saying for many years is let's work together from the ground up. So the goal of these resources, particularly this afternoon, is to think about all the potential partners and the resources you may have and to really take these tools back with you, and hopefully, they'll prove useful to you. So, let me take a minute for a couple of questions and then we'll move on to a second presentation. Yes DR. LOOK: Jon, before, I came from Indiana and I'm still Kathy Look. DR. KERNER: Glad to know that hasn't changed. DR. LOOK: Me too. I sat down and talked with the state's epidemiologist that is associated with the cervical cancer project. And it was very helpful for the CDC to go through this work and name these three counties for me. But when I look at my epidemiologist contact, two of the three counties, she says there is not a rural problem, because she calls the rates unstable because there are so few deaths in these individual counties. DR. KERNER: Right, and I think -- . DR. LOOK: And this is hard if the local people who touch this issue every day say, well, we don't think this is a problem. And I run up against this issue, now, two or three times a month. But she teaches it five days a week. How do I convince her if she says there's not a problem because the rates are unreliable DR. KERNER: No. And I think that's an excellent point. We actually heard that from another state. I won't name that state, but I got a lot of grief about this. DR. LOOK: It's right next to our state because I heard from them too. DR. KERNER: Yeah. I'm sure. Yes, I think it was actually a movement to try and persuade people not to come to the meeting. We recognize, and Susan made this point in the beginning of her talk, that because cervical cancer is a rare disease, if you look at anything in one-year periods -- you're absolutely right. The rates are bouncing up and down like crazy. They're very unstable. And I think that's what your epidemiologist is making reference to. But you will recall that the maps that we provided to you were for a period -- 1950 for whites, and 1970 for African-Americans, through 1998. And there are a set of maps also which showed five-year time periods for that. And the point is for those time periods across all those many years, there is stability in the estimates and the fact that they haven't changed. I didn't show you a map that shows you every five-year period from 1950 all the way to 1998, but when you look at every five-year period, the pattern is remarkably the same. So the argument I would make back to your epidemiologist, and I hope it would be compelling, is that they're absolutely right -- . In any one year, any

one county might be appearing or disappearing because the rates are unstable at one year. But when you average across years and you see the same pattern for 50 years, I'm sorry. It's not a question of rate instability; there is something going on here. DR. LOOK: She argues that there have to be 20 deaths per unit of time. So when she looks at 1979 to 1998, which is the 20-year unit of time, there are many counties in the state of Indiana which do not have 20 deaths. Cause they're itty-bitty little counties and nobody lives there. So I mean, it's hard. And I will be glad if anyone at any of the microphones or anytime today can give me any words of advice to convince my epidemiologist because when she gives me these 20-year data, that argument is not going to sell. DR. KERNER: Okay. Well, I'm going to challenge my staff, the staff of the NCI, to think about this question when the federal group meets this morning. And perhaps we can provide some information back to the state epidemiologist that will be more persuasive than I am. Is that a reasonable challenge Thank you. MS. SAMMONS-POSEY: Jon. I like these little county things. However, I have 21 counties, I only got one county sheet, and I don't know why they picked Ocean County. If you're looking for rural counties, I definitely got six, and I wouldn't classify Ocean as one of them, so I don't know how they came up with that one. Plus, is there a possibility of the information that we got for that county whether its right or wrong or somewhere in between -- is it possible to get this information for all of our counties in our state Has it been done for those or just for this point of this exercise for that particular county DR. KERNER: First of all, if you have 21 counties, you should have gotten three. We will check on that because there is no way that you should have only gotten one if you have a total of 21 high mortality counties in your state. If that's what we told you, then there's something wrong. Cindy's looking at me with that strayed look. We're going to look. What MS. VINSON: (Inaudible) DR. KERNER: How many did they have Did they have only one All right. Well will you check on that We'll get back to you. But you're absolutely right. This is the point of an exercise. We thought about and tried to figure out how we could do all of this, but this took, actually, a remarkably long time, for each country to track down all of this information. So our goal with you is to say that we've started the process. If you think it's valuable, you finish it. It's a partnership. And we've started it. If there are other things -- . For example, we just recently got contact lists for all the USDA cooperative extension agents. That's something that we will share with you because we are actually having -- . USDA came to NCI to talk about some collaborative efforts around breast and cervical

cancer screening using the USDA cooperative extension agents. So we will absolutely get that information to you as we come at a national level. But really the point of this was to sort of stimulate you to think, well, what are the local resources we could pull together that could help us with our efforts. Yes. FEMALE VOICE: I just needed some more information about these counties. If it's for an exercise, that's great. If it's for me to do some action plan, you know, why these counties Were they random Random high risk Are they worst counties And then, if it's just for today, as a model, then, I just needed more information than I was given. DR. KERNER: Okay, well that's probably because Steve would have done a better job than I did in his presentation. But, as I recall, and Cindy can confirm this, if she can hear me, we selected the counties out of the group of high mortality counties. And we tried to look for counties that seemed to be a little more resource rich and a little bit less resource rich. So we picked counties that we thought, as they were looking through, sort of the number of organizations and things that were there -- Am I getting this right MS. VINSON: Correct. We actually talked (inaudible). DR. KERNER: Right. MALE VOICE: What it was is an exercise. DR. KERNER: It was an exercise and the goal isn't to say, your goal is to look at this stuff, and say, okay, this is interesting information and in this county, how might I use it. If I had this information for every county, as Doreleena said, how could I use this information And this will be particularly relevant in the afternoon session. How could I use this information in my one-year action plan. FEMALE VOICE: We can get this for counties that we can really work with, though. MS. VINSON: (Inaudible) DR. KERNER: Can we get that copied MS. VINSON: (Inaudible) DR. KERNER: All right. We'll hand that out to you. I hope that helps answer your question. DR. HARFORD: Joe Harford from the NCI. Jon, I was just wondering, is there, as a resource for this group, any place where they could find a listing and maybe even a searchable database of sta